

FINAL REPORT

UTAH HEALTH STATUS SURVEY ON ETHNIC POPULATIONS -- QUALITATIVE COMPONENT

Prepared for:

UTAH DEPARTMENT OF HEALTH
BUREAU OF SURVEILLANCE AND ANALYSIS AND
STATEWIDE ETHNIC HEALTH COMMITTEE

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Background and Description

Purpose: During May, 1997, the Utah Department of Health commissioned a University of Utah study through a competitive bidding process to:

- ° Enhance the understanding of health issues that are important to Utah's racial and ethnic populations, and
- ° Inform the design and methods of subsequent efforts to collect ethnic health-related information in Utah.

Our purpose was to give voice to Utah's racial and ethnic minority populations in the process of planning and delivering *health system*¹ services in Utah. We incorporated an open, inclusive qualitative-interview-and-group-discussion process to encourage broad representation across and within diverse ethnic populations. Our information synthesis, validation and reporting methods were designed to facilitate understanding and simplify action steps. We sought to minimize health system or study team bias throughout. Study results were intended to serve as one of several resources available for planning health system services and data collection activities in Utah.

This report focuses on ethnic health issues and suggestions for responsive action. A second report focuses on methodological issues and suggestions for completing the larger, quantitative phase of the ethnic health survey process.

¹ The term "health system" as used in this report includes any and all agencies, organizations, individuals, and resources that can be applied to meet the health needs of Utah's racial and ethnic minority populations. Health system services and activities include the primary, secondary, and tertiary health care services of direct providers; additional disease prevention and health promotion activities of non-health care providers; the related activities of administrators, support staff, and volunteers; personal, family, and community health-related behaviors; local, state, and federal policy makers; and activities related to the organization and financing of the health system in Utah.

Need: Health-related information specific to Utah's ethnic populations is needed to successfully plan and deliver health system services to these populations. Health system efforts to collect useful quantitative data have been full of challenges. Small population sizes, diversity within each population, difficulty in locating and accessing population members, the high costs of reaching sufficient numbers of participants, cultural factors, and language barriers have all contributed to a continued lack of useful information. Without continuing investments in identifying and meeting the needs of these growing populations, Utah would experience an even greater demand for high-cost services in the future.

Delimitations: This study was purposely and appropriately limited by both the time and resources available to it. The study was designed to *identify* health needs and data collection strategies in five health system-designated ethnic populations. We used purposeful sampling techniques and qualitative data collection methods to identify health issues. We did not randomly sample participants from a population in an attempt to develop statistical confidence in generalizing results to all members of that population. We did not conduct "research" in order to compare results to any previous studies or to generalize results to any other population.

We did not artificially introduce topics that were not first introduced by study participants in order to examine all possible health-related topics of interest to all possible audiences. We did not conduct an epidemiological study of the incidence, prevalence, or distribution of disease among ethnic populations in Utah. We did not study the availability or quality of health system personnel or services to ethnic populations. The scope of this study was limited to identifying health needs and data collection strategies that are important to Utah's racial and ethnic populations. Although we did involve health system representatives from or serving each ethnic population, this was not a study the health system. This study was only one step among many toward addressing the health needs of ethnic populations.

Limitations: The great diversity in health needs and actions among people *within* each study population emerged as the greatest limitation on the breadth and depth to which we were able to examine health issues. Such factors as gender, age group, country of origin, documentation status, generational status or length of residence in the U.S., geographical location within Utah, level of family or community support, unmeasured psychological characteristics, health status, cultural factors and the varied availability of health insurance and health services within each population and sub-group made it impossible to simultaneously address all issues with all possible combinations of ethnicity and these other characteristics. Thus, the level of analysis for this study remained the ethnic populations as designated in the Department of Health's Request for Proposals. We feel that this limitation was appropriate given that this was a first step of several anticipated for the future. And, the costs of specifically addressing each factor and combination of factors within each population and sub-group within populations would have been unacceptable and -- for the purposes of this phase -- relatively unproductive.

The second greatest limitation we faced was the short period of time available to identify, access, and gain meaningful participation from representatives of this broad diversity. Developing trust and comfort in sharing personal information with strangers whose motives may initially be suspect -- regardless of their ethnicity -- takes time and considerable effort. We designed and completed this study to overcome these challenges by identifying, contacting, and offering confidential participation to more than 400 members of Utah's ethnic populations who, as a whole, could represent this great diversity.

Point of View: The health issues examined during this study were, by design, only those offered by ethnic minority study participants as important to them during personal interviews or group dialog sessions. We avoided suggesting topics or "putting words into their mouths." By design, we avoided examining these issues

or introducing other issues from the point of view, say, of non-minority health system providers, or our own. Our purpose was to learn *from* ethnic populations while giving voice to their needs and suggestions about health system services and activities in Utah. We maintained and reinforced this point of view throughout. It was our intent to give voice to under represented populations in the context of their own constructions, and to present results in ways that tend to reflect and emphasize participants' actual experiences with the health system in Utah.

Participants: The study populations that were designated in the Department of Health's Request for Proposals, and named here based on study participants' overall preferences, included African Americans or Black Americans; American Indians; Asian Americans; Hispanic/Latino/Chicano Americans; and Pacific Islander or Polynesian Americans. We made separate study of three additional groups whose diversity from their main population in geography, language or culture warranted separate study; Southeast Asians, Seasonal Farm Workers and eight nations, tribes or bands of American Indians. In all, study participants stated that they represented more than 20 different races, ethnic groups, or separate cultures. We did not systematically identify or record all participants' affiliation, and expect that we would have found an even greater diversity among participants if we had.

Staffing: Project staffing included the principal investigator, a project coordinator, and two project associates who were experienced in working as a team on similar projects. Seven community liaisons joined the team for this project, one for each population or group participating in the study. All eleven team members were variously involved in contacting community participants, nurturing their understanding of the project, and organizing data collection activities. All were instrumental in building trust and comfort among study participants and nurturing their meaningful participation. Along with many of the participants, all team members were involved in the synthesis and reporting of study findings.

Cultural Sensitivity: We took several steps to ensure cultural sensitivity in all study activities. First, we applied strategies to allow participants to discuss information in ways that would allow it to remain grounded in their own constructions and not an artifact of our own. At each step, participants were encouraged to guide the scope and direction of discussions toward topics of importance to them. We offered repeated opportunities for them to validate data summaries and offer additional insights. Second, we consulted with key informant representatives of each study population to ensure that our methods for identifying, contacting, recruiting, involving, and rewarding participation in the study were appropriate and culturally sensitive. Third, we actively involved community liaisons who were representative of each population in all phases of the project. This involvement alone did not guarantee cultural sensitivity, but we feel our selections of liaisons and the other measures that we took minimized our concerns. Fourth, the documents produced during this project were subjected to review and comment by persons representing a broad diversity of cultures and viewpoints. We paid particular attention to ensuring that we were open, alert, sensitive and responsive to the unique needs of all persons with whom we came into contact.

Approach: We completed the project in four interrelated, and somewhat overlapping phases. First, we reviewed existing literature to develop a general understanding of the health issues and data collection strategies that may, or may not, apply to Utah's ethnic populations. Results of this information review also served to guide the scope and content of our data collection strategies. Second, we conducted personal "key informant" interviews with members of each study population. We interviewed a representative mix of health system providers, consumers, and community leaders within each population. We then validated results with each individual participant and developed a synthesis of key informant findings. During the third phase of the project, we facilitated group sessions within

each study population to clarify, validate and expand on key-informant findings. For geographic, language and logistical reasons, we tripled our personal interviews in two populations in place of large group sessions. Finally, we made follow-up validation contacts with 30 selected study participants to further refine and validate findings, and developed seven population- or group-level syntheses and one overall synthesis of findings.

Outcomes: The results of each phase of the study informed the direction and methods of the next, to continually enhance the quality and usefulness of project findings. This inclusive process was intended to ensure that the findings that emerged would reflect each community's voice, rather than the government's or our own. We remained flexible in all phases of the study in order to respond to the needs and wishes of ethnic populations. Thus, the synthesis presented in this report is the best reflection of the health issues faced by Utah's ethnic populations we could develop given what were appropriate limitations on time and resources available for this project. It represents the first step in what hopefully will be an ongoing effort to an inclusive and meaningful involvement of ethnic populations in planning and implementing strategies to successfully address the unique needs of Utah's diverse racial and ethnic populations.

Literature Review

Purpose: We conducted a focused review of related research to identify ethnic health issues that had been examined in other populations, and potential improvements to collecting health-related data in Utah's ethnic populations. The review was *not* conducted in order to produce an inventory listing of related publications or a written analysis of related research. It was used only to plan and guide study activities. The review was but one of several tools we used to guide the scope and strategies of our qualitative data collection efforts.

Method: We employed a variety of search criteria and methods to access information that would inform our decisions about the design, methods, and suggestions of this project. It quickly became apparent, after initial key-word searches of on-line social science and medical databases, that a rich body of knowledge relating to ethnic health issues and data collection strategies was available. This information was spread throughout the literature, but we were able to identify quality sources and access information without undue complications.

Findings: The review revealed a substantial body of knowledge related to quantitative and qualitative social-science data collection strategies in ethnic populations. The maturity of this literature is evidenced by the several, high-quality monographs and book-length publications presenting and critically examining findings from a broad representation of the social and behavioral sciences. During the early 1990s, this work was complimented and enhanced in the context of health data collection, through a federal government investment of \$45 million dollars in support of an ethnic health data initiative administered by the National Center for Health Statistics. In a separate report focusing on quantitative survey methodology within ethnic populations we attached a selected listing of publications that can most directly guide future ethnic health data collection efforts in Utah.

We found a substantial number of medical research articles through key-word searches using ethnic and minority descriptors, but most included only brief mentions of statistical breakout results for ethnic populations. The majority of studies were not conducted to address ethnic health issues, but many studies reported racial and ethnic differences in the incidence and distribution of specific diseases. Still, there is a growing literature addressing cultural issues in the context of health care and prevention. The findings most relevant to the current study were that, in general, members of racial and ethnic populations tend to

access medical care later in the course of an illness or disease than the general population, and poorer health outcomes are a direct result.

We found no evidence of comprehensive, multi-population studies devoted to ethnic health issues or studies that would cause us to adjust the scope or study methods outlined in the Request for Proposals or our original study proposal.

Key Informant Interviews

Purpose: We conducted key informant interviews to 1) identify and begin to understand the health issues that are important to Utah's ethnic populations, and 2) identify potential strategies for successfully obtaining useful health-related information within each population. Through these interviews we also began to build trust and support for meaningful community participation in this study, and learned about how best to introduce and conduct the study in each population. Results of the key informant interviews also helped to inform development of subsequent group protocols and our other qualitative data collection strategies. Our key informant contacts were indispensable in building a culturally appropriate network through which we were able to identify community liaisons and study participants.

Method: The key informant interview process involved a series of steps including identification, selection, contacts and scheduling; design and piloting of the data collection instrument; interviewing; and analysis and reporting. Each of these steps was outlined in detail in our original study proposal, and are briefly summarized here.

Identification: We identified potential key informants through several processes, relying at first upon initial contacts with persons whom we were already familiar through our previous work; recommendations of state and local government agencies; local minority-serving community organizations; and other community

resources. We also advertised publicly through flyers placed in communities, and through a mailing to more than 250 ethnic health-involved persons throughout the state. We identified three types of key informants within each population in order to obtain a broad perspective of health issues:

- ± Health system service providers representing or frequently working with members of one or more study populations;
- ± Health system service consumers from each population; and
- ± Community leaders representing service organizations, faith communities, and other culturally relevant groups.

Selection: We employed purposive sampling strategies that are somewhat similar to the “snowball” sampling technique used to meet a quantitative sample size quota. This emergent process contrasts with a statistical random sampling process for which all potential key informants would need to be identified. This was not possible during this study. Even if it were possible to enumerate all potential key informants for this project, a simple random sampling would not begin to ensure that the people selected could provide the full range of information desired or represent the diversity within each population. We built upon initial contacts to reach a broad variety of persons who could provide useful information about each population. Thus, representativeness was the result of our willingness to seek out new contacts rather than through any statistical guarantee. In all, we formally identified and contacted more than 400 potential study participants representing the broad diversity across and within the five study populations. We made special efforts throughout the study to ensure participation from the broadest representation of ethnic and cultural diversity possible.

Contacts and Scheduling: We first contacted up to 12 potential key informants for each study population by phone or in person, when it was appropriate. To allow potential participants to make an informed decision about their participation, we introduced the study's purpose, and answered any questions about the study. Once these initial contacts were made, we followed-up with from six to eight people from each study population based on our need for broad representation within populations and each person's potential for providing needed information and insights about the study population. We asked that they set aside 90 minutes for a semi-structured interview, and requested that they assemble any written records or other materials that would be helpful to us. We followed up with repeated contacts as needed to set a time and place for the interview. Once an interview was scheduled, nearly all key informants were present and available for the interview at the appointed place and time.

Design and Piloting of Data Collection Instrument: We developed a draft interview protocol based on literature review results, meetings with state staff, the Ethnic Health Committee, the Ethnic Health Status Survey Workgroup, and informal talks with potential key informants. This draft was fairly detailed, anchored by general, open-ended questions with specific follow-up questions on all identified topics. The draft was less structured than we had originally anticipated, based on the natural quality and depth of information we obtained through our initial telephone contacts with key informants. We piloted this draft with six key informants, and it became very clear that an even less structured, conversational approach would work best, because participants understood the purposes of the study and were very well prepared to discuss health issues and data collection strategies without much prompting or guidance.

We found it to be the most useful to ask very broad questions, listen to responses, formulate probes for specific information based on what had been said,

listen to additional responses, and then begin to verify what had been said and to fill gaps in understanding. This conversational interview style worked well with persons from all walks of life -- something we had not expected through previous experiences but were happy to discover. The basic questions that we asked during each interview can be *informally paraphrased* as asking:

- . *"What health issues are the most important to [ethnic population name]?"*
- . *"What about prevention?"* and
- . *"How should we go about collecting health information from members of the community?"*

Our follow-up questions and probes easily led to more specific comments when needed, and helped to ensure that both the interviewer and the key informant were satisfied that each person's story was being told. We employed and refined this data collection strategy throughout the key informant interview process.

Interviewing: In general, initial interviews within each population were conducted by the principal investigator. These initial interviews were conducted with more highly acculturated key informants from the community organization or health provider segments of a population -- persons who were more used to discussing these issues and sharing their thoughts with strangers. We had anticipated that interviews with consumers would be more challenging and scheduled them for later dates, but discovered that this assumption was unfounded. During the initial interviews, the community liaison for that population observed the interview process and served as a note-taker. Community liaisons quickly moved into the interviewer's role, and then to conducting interviews on their own. These interviews were conducted in communities throughout the state, at locations selected by and at the convenience of each key informant. The

principal investigator conducted approximately one-third of the interviews to ensure sufficient grounding in the process and findings within each population.

Data Analysis and Reporting: Our first step in the analysis of key informant results was to submit a written summary of the interview to the key informant for review and comment. This allowed participants another opportunity to clarify and add to the information we had received from them. We then organized the key informant-validated data into a *preliminary synthesis* of findings. This synthesis was a summary presentation of findings organized by the health issues that had emerged during the first 33 of our 57 key informant interviews. This preliminary summary of results was presented and discussed during a meeting of the Ethnic Health Status Survey Workgroup, but was not intended to be representative or distributed as findings from the study. The purpose of the key informant synthesis was to guide subsequent group discussions that would clarify the importance of each issue to a population, and to provide a basis upon which we could validate the accuracy completeness of this information with participants.

Results: We completed a total of 57 formal key informant interviews, well-distributed across and within each of the five designated study populations. We also completed 34 additional substantive discussions with other key informants by telephone as we sought additional information or clarifications toward the end of the study. The 91 key informants were very interested in the study, enthusiastic in their participation, and very helpful in all regards. No one refused to participate, but a few potential key informants whom we had contacted said that they were interested, but were "too busy" to participate. Throughout the study we made special efforts to conduct additional interviews and validation contacts to fill gaps in understanding or representation. The results of this thorough and inclusive key informant process were compiled into a preliminary synthesis of findings which was used in planning and conducting subsequent group sessions.

Group Sessions

Purpose: Group sessions were conducted to 1) hear from a broad diversity of ethnic community members about important health issues and data collection strategies, 2) stimulate discussion within small groups to allow population members to clarify and validate the importance and meaning of the issues to the population, and 3) validate and clarify our understanding of the health issues and the data collection strategies they suggested. The results of each group, including quotes of statements and illustrations through stories, were used to summarize and illustrate the issues for each group and contribute to an overall synthesis of study findings.

Recruitment, Contacts, and Scheduling: Many of the strategies for participant identification, contacts, and scheduling were similar to those we used in setting up key informant interviews. These steps were, of course, much more complex and involved due to the numbers and diversity of participants in each group. We applied a purposive sampling procedure to ensure participation from all segments of each study population. The key informants and our community liaisons were very effective in identifying, contacting, scheduling and obtaining participation from ten to 35 population members in the group sessions.

Session Organization: Each group was designed by community members to ensure that the day, time, location, incentives, refreshments and “style” of the meeting were in keeping with the personal and cultural preferences of the group. Key informant results for most populations indicated that the community liaison should serve as host and open each session with an introduction of the purpose of the session and how results would be used. For most groups it was equally important, from the participants’ point of view, that the principal investigator, representing the expertise of a respected educational and research institution, serve as facilitator for discussing ethnic health issues and data collection strategies. We

discussed this general strategy with the Ethnic Health Health Status Survey Workgroup which approved its use in this study. Sessions that were conducted in a language other than English were co-facilitated by the bi-lingual community liaison for that population.

Session Format: Each session followed a similar path, beginning with the community liaison convening the meeting and introducing the study. The session facilitator would then answer any questions and obtain voluntary consent to participate through a process approved by the university's Institutional Review Board. Most groups then quickly gathered into one of three small groups to discuss and expand on the synthesis of key informant findings related to health care issues, prevention issues, and data collection strategies. These small-group discussions lasted approximately 30 minutes, focusing on discussion of whether or not each identified issue was important to that population, and telling about experiences to illustrate how each issue had affected individuals from the population. This small-group strategy was successful in encouraging active participation from all group members -- something which does not always occur in larger groups. The entire group then reconvened for the next 30 to 60 minutes to clarify and discuss the issues again in the large-group setting. When time was available at the end of the session, the group attempted to rank or prioritize the issues according to an agreed upon criterion, such as which issues were most important or needed to be addressed before others. Interestingly, participants were usually unable to prioritize the issues, ultimately concluding that all issues were important and none could be ignored or "put on the back burner."

Session Populations: Seven separate group sessions were held with African Americans / Black Americans; urban American Indians; Asian Americans; urban Latinos; documented and undocumented Seasonal Farm Workers; Southeast Asian Americans; and Pacific Islander Americans. With the approval of the Department

of Health we did not reschedule the poorly attended Asian American session, but completed seven additional key informant interviews (for a total of 14) and a small-group session with another seven participants, to complete the group session process for the Asian American population. Early in the project, an eighth group -- which was to convene rural American Indians from across the state -- was replaced by 12 additional rural American Indian key informant interviews and one small-group session involving five members of one band. This decision was made in consultation with the Ethnic Health Status Survey Workgroup.

Session Participation: Descriptions of the participants and the language used during each group are listed below:

African American / Black American: Ten African/Black Americans participated in this session. Seven women and three men ranging in age from 20s to seniors participated, representing a mix of community workers and health system consumers. The session was held on a Monday evening at the Central City Community Center in Salt Lake City. A small buffet of traditional 'soul' food was offered to participants at this dinner-hour session.

American Indian: A total of 22 urban-living American Indians from several nations/tribes/bands participated in this session at the Indian Walk-in Center in Salt Lake City. Fourteen women and eight men ranging in age from teens to seniors participated, representing a broad variety of health system providers, consumers, and community workers. Snacks and soft-drinks were provided to cool participants during this hot Summer evening session, which was conducted almost entirely in English.

Asian American: Seven people participated in this group session which was conducted by the Asian American community liaison. Participants included four of bi-racial decent with parental ties to China, Hawaii, and Korea; a Chinese American professional who is married to a Caucasian; a Korean American, and a Japanese American. The session was conducted in an empty restaurant convenient to the group.

Latino/Hispanic/Chicano: Eleven participants, eight women and three men convened in the conference room of Centro de la Familia in downtown Salt Lake City. Participants included a physician and community service

professionals ranging in age from thirties to fifties, with two recently immigrated young women also participating. A snack of salad and pizza was offered during this dinner-hour session. This session was co-facilitated by the Director of Centro, and was conducted in both English and Spanish, with participants translating for each other.

Pacific Islander American: This session was held on a Saturday morning at the Sorensen Multicultural Center in westside Salt Lake City. Thirteen participants ranging in age from teens to seniors represented students, clergy, health and social service providers and consumers. Eight women and five men participated and then shared a take-out meal of Pacific Islander food from a neighborhood restaurant.

Seasonal Farm Workers: This session was originally scheduled for a week-day afternoon near Layton, but the workers stayed in the onion fields much later than planned. The session was held the next day, and was facilitated by a bi-lingual AmeriCorp worker with assistance from two bi-lingual Latino women, all of whom work with this population on a daily basis. A total of 20 participants, both men and women, ranging in age from 20s to 50s participated in this Spanish-only session. A snack of rolls, meats, and chips was appreciated by the participants.

Southeast Asian American: Thirty-four Southeast Asian Americans participated in this Sunday afternoon session held in the banquet/meeting room of a westside Salt Lake City Chinese/Vietnamese cuisine restaurant. Participants' ages ranged from teens to seniors, none of whom spoke English during the session. A well-respected community leader organized and facilitated translations between the English-speaking principal investigator, and participants speaking Vietnamese and other Southeast Asian languages. After the meeting, participants enjoyed a traditional meal of rice, vegetables, and meat dishes.

Data Collection: Information was recorded in three ways: 1) audiotape recordings of each meeting except the Asian American and Seasonal Farm Worker meetings, 2) debriefing and interpretative notes by the principal investigator/group facilitator, and 3) detailed notes taken by an experienced project staff member. Nearly all participants at all sessions were actively engaged in the discussions, freely offering their personal perspectives, relating stories to illustrate their points,

discussing issues with other participants, and covering a broad range of issues. It was truly a joy to facilitate these sessions.

Analysis: Our main goal for the analysis was to organize and summarize results in ways that could readily facilitate understanding and simplify action steps. It was equally important to avoid “filtering” or “massaging” the data into a form that did not directly represent the intended message conveyed by group session participants. We began the analysis by listening to the tape recordings and transcribing verbatim the comments, statements, and stories of participants. For each group session, we then organized these data by topic under *informal* descriptive headings. These headings were derived primarily from the key informant synthesis, and reflect the general topics discussed in each group session. As a final step in the group-level analysis, we contacted eight additional members of each of the five study populations to validate selected results summarized in a checklist-ranking format. This step revealed no inconsistencies, inaccuracies, or omissions in the findings from group sessions.

Reporting: The results section of this report begins with separate group-level syntheses of findings related to health care issues and prevention issues -- one synthesis for each population. A separate by-population synthesis of findings related to data collection strategies follows the “health and prevention issues” syntheses. In each synthesis we chose to include most or all participant statements and stories on a topic rather than editing out or reducing the number of comments presented in the body of the report. We did this because the statements as a group tell a story without help from us. To facilitate focused discussions of the issues, we also present an overall project synthesis. This overall synthesis consolidates the group syntheses into a single synthesis of important health issues, with representative comments from each population. We believe that each of these syntheses can be useful planning efforts to address Utah’s ethnic health issues.

RESULTS

Health and Prevention Issues

In this section of the report we directly give voice to Utah's ethnic populations through verbatim quotes of the comments, statements, and stories that study participants offered during interviews and group sessions. We have tried to organize and summarize results to facilitate understanding and simplify action steps -- without introducing bias in reporting results. We present a separate synthesis of health and prevention issues for each of the seven study populations, a by-population synthesis of findings related to data collection strategies, and an overall summary synthesis of study findings.

Please Note: Statements in "quotation marks" are direct quotes from audiotapes of group sessions or interviews. Statements not in quotations are either English translations or paraphrased comments when the exact quote could not be reconstructed or verified. Topic headings derive from key informant results, but represent study team wording in some cases.

African American / Black American

Cost issues

"Medical care is so expensive that old folks and poor folks cannot afford it."

"Patients wait too long for services [but] the doctors don't wait for the money."

Prejudice and discrimination

"My experience has been that there is a skepticism on their part. They seem to be reclusive at times not knowing, seeing someone black in the office for the first time along with other patients. For me, I was being stared at and looking as if 'Well,

what is she doing here?’ kinda thing. So, I don’t think it is the same; My feelings are that here in Utah it is not the same.”

“You can also tell by the doctor’s body language if he is relaxed or uptight.”

“It seems that when African-Americans go to the doctor’s office they will serve all the whites first and then help the blacks; even if the patient is on time for the appointment, [they] make [you] wait.”

“[After] seeing the doctor multiple times, and the doctor not helping patient telling them ‘its all in your mind;’ but the white lady gets treatment and prescription and blacks cannot get any treatment.”

“[The clinic] gets tired of you complaining [so they] put you in a room for two hours before they see you.”

“[They] forgot about a patient, waited too long in emergency room.”

“[During my visit], I have to let them know that I am here.”

Lack of people of color to relate to at all levels in health system

“When you are ill you need doctors around with confidence, especially when you are in a weak situation. You need to speak to people who can assure you of your situation.”

Many mental health providers do not know enough about the Black culture to provide adequate treatment.

Providers need to know something about the culture especially regarding religion and family which is very important to Black culture.

If you work in health care and help colored individuals, you get accused of favoritism or preferential treatment.

If the doctor doesn’t take Medicaid, or know the culture, he should help find one who does.

Consumer lack of knowledge about health system

People still think that mental health care is only for people who are "crazy". She tried to explain to them that mental health covers a lot of things like depression, family matters, etc.

System providers' lack of knowledge about disease and outward symptoms

"I don't think they know the culture, I don't know because one of the doctors I talked to said 'You know, I haven't had much experience dealing with Black people;' and it is very important for me because I had an infection in my skin and he didn't know it. You can't tell right away whether black people have an infection and I knew I had an infection, you know, because he says it's hard for him to tell."

"I remember when I had my first baby, unfortunately I ended up with chicken pox, and this was kind of a joke for us. I got to the hospital in labor and I had these bumps on my skin which I didn't know what it was because it started coming on the day before, and I was kinda worried because here I am in this state; no family, my first time away from my family, and I told them that I had the bumps on my skin, and then they call the dermatologist in and he checked it and he said 'It looks like chicken pox, but I have never seen chicken pox on a Black person.'"

"One of my kids...has Sickle Cell and the first time she went to the hospital here I actually had to tell them everything they had to do. We waited there for over an hour...[and] I had to call them and say 'Listen to this' you know...[and] they have all these interns coming in and it is the first time they seeing, actually seeing somebody with Sickle Cell. [It's] something that can kill you on the spot. If your blood drops too low, you don't have any time for interns scrutinizing and deciding whether this is something they need to look into."

"My doctor was out of town and so I was seeing who was filling in for him and he says 'You've got the worst case of high blood pressure I've ever seen in my life!' I was thinking 'Well, gosh, he must have not dealt with people with real serious blood pressure before.'"

"Hypertension - the doctor needs to understand why diet, stress, are so important when it concerns blacks and hypertension."

"So I think its knowledge again. I think they need to be more exposed to people of color in order to understand the various illnesses that we have."

System lack of understanding of culture

"Doctors don't have enough experience to meet the needs of African-Americans."

"If they can't or don't have any experience they need a network or referral system of people who do have experience and can help."

Lack of equity in treatment

"When calling to make an appointment [they] want your name, number and insurance; [you] have to sound intelligent, know what you're talking about or you don't get an appointment."

"It is so hard to get an appointment. Need a phone referral service to help save money."

"Then they get tired of you sitting out there complaining about you trying to get in the office [and] they put you in there and go off and leave you and you stay in there for hours."

"I remember one time I went to the emergency room. I think they forgot about me, so by the time they came in to see about me I put my clothes on [and] he said 'Where are you going?' I said I am going home, I have been waiting and waiting and waiting."

"When you do get in to see the doctor, you came back to him with the same complaint that you had last month. He's gonna tell you the same thing this month that he told you last month; 'It's in your mind.' Now, you can't sleep, you're wetting all over yourself and he leaves you with 'That's all in your mind.'"

System lack of respect for people of color

"I got the impression that whenever I've gone in a couple of times they were looking at me like 'How are you going to pay for this?' You know, there are these kinds of questions that come up, and without even asking me 'What is your problem?' they are more concerned 'Do you have insurance?' 'What kind?' 'What is the coverage?' and all that. Once you get past that hurdle then things change; 'Well, you got insurance, then you're covered. You pay your co-pay and hopefully you get to see a doctor.'"

"Even when you call to make an appointment...basically, once they ask you your name and phone number...a lot of times the next question is 'What insurance do you have?' and the minute you say you don't have any insurance...If you sound like you don't know what you're about you can forget it. Automatically, there are no appointments."

Use of traditional remedies

"I think for the most part, rather than dealing with the doctors, quite a number of our people use their own traditional means or family to try to help them to umm, alleviate some of the suffering...rather than go to the doctor."

Delay due to discomfort with accessing services

"Not so much traditional remedies, so much is that you don't feel comfortable in the setting because you know from experience that you're gonna be gawked at because you're the only Black person in the waiting room. It's just a combination of things."

Distrust of health system and care providers

"There are few caring and compassionate doctors. The system itself is out of control."

"No one believes bureaucrats. They have a credibility problem: Tuskegee, Atomic Testing."

"I do not have a lot of faith in the medical system."

Seniors are sensitive to anyone from outside, black or not, "taking over" even food for events

System complexity

Poor system to get to a doctor. They always want a referral from a family or general doctor. Why do you have to pay for GP visit to get to an eye doctor? The only way to get around it is to go to the ER.

We would like a doctor that could be called and give the symptoms so that he could tell you who to call. Want to avoid that extra payment for referral.

Insensitive doctors

The provider doesn't have to be Black, just sympathetic.

Prevention

"I think it [prevention] needs to be made more personalized in addressing [individual needs]. Information should be available that's more geared to African Americans. So, I think information should be culturally available for people by their culture."

"When they put these programs together they need to base those programs on our needs with, hopefully, input from someone that is a health authority that is, you know, African American, and the wording is a big point I believe."

"A specific health fair held to address the prevention of disease that are specific to the African American community....It needs to be more often and more frequent and secondly that there is a great deal of diversity in the community so it ought to address a lot of topics and not try to cover all of the population in one big swoop."

"What tends to happen is this token type of mentality that, 'O.K., we've already funded one program that is related to that.' so they figure that they are doing enough."

"They need to be accessible so that we can get to them."

"Some of the cultural activities that are organized on a regular basis you probably could piggy-back on those because people generally tend to come out to those. So, take advantage of gatherings that would already be in place."

"The fact that the information is not as specific to some communities really short-changes those communities because the information that is available would perhaps be helpful in a general sense, and so you don't go because you know that there isn't anything that is as specific as you would like, so you also miss the general information in addition to not getting the information that is real pertinent."

"I was just thinking another place where we can get some of the information is simply from our doctor's office."

"When I was having my baby...I let [the doctor] know that I had a baby with Sickle Cell, and all throughout my prenatal care he never once brought up that

information, never once. I don't think he had any idea as to the seriousness of the fact that I'm saying my child has Sick Cell."

"Even at the doctor's office there is nothing, you know, so that is one of the places that you need that information, you need that prevention information."

"I think that if you get the information to the ministers of the church...because people listen to the minister of the church. That would be one way to help."

"I think it is through community service announcements that have ethnic people involved in the commercials so that you can see someone like you."

"Printed material that have Blacks involved with pictures of black folk on it would help as well."

"The modes of addressing any given population are usually the same...and it has to be a mixed medium.... You would have to take into consideration that some people get most of their information from reading, some people listen to the radio, some people watch TV."

"The exclusion hurts those that are inter-racially married and their children."

"Needs to be personalized and more geared towards African-Americans and women."

Programs and services are not visible in ethnic communities.

American Indian

Cost issues

"Indians feel shame when they cannot provide for their families."

Lack of knowledge to access health system

"One main thing we brought up for prevention was Medicaid workers that are sensitive to Indian issues and Indian people, someone they could trust to help them along to get access to the care. Sometimes we just need more help to get a birth certificate, know how to use insurance, apply for assistance."

System mis-perceptions about access to care

It is a false assumption that all American Indians are served and served well by the federal government. Recent IHS cut-backs and closing of SLC Indian Health Center.

There are no resources for rural tribal mental health.

Inadequate access to experienced physicians

"American Indians are under served in health agencies."

In rural areas especially, American Indians must rely on nursing care services

Discrimination

The attitude among rural providers is that American Indians do not deserve equal health treatment due only to being American Indian.

Health plans apply pressure to disenroll disabled American Indian clients.

Lack of voice in system decisions

The state is not involved. Surveys are never ending with no positive outcomes that will benefit people. There is frustration with the lack of follow-through on promises or word: "There is life after Provo."

"The whole point of this was this was to go into the community and have the community say what they want, whereas before on most minorities, especially the Indian community, they must take it for granted 'This is what they want.' They never asked."

Distrust of system

"As Native Americans we are totally mistrusting, because of what has gone on with our people. We voice our opinions, 'We want this, we want that;' but what's going to happen? Are we going to get what we want? What's the end result?...Nothing."

Providers insensitive to cultural and gender issues

"An injured boy came into the hospital...has long hair. While nurses wanted to cut it off without any understanding or respect of what the long hair represents. Needed to talk with Indian person."

"Traditional values; Indians withdraw into themselves when the need arises for medical attention, or don't ask for help. The white doctors or nurses need to be trained to understand or recognize these values."

Modesty of women.

System lack of knowledge or respect for cultural values

"I see a lack of respect for our culture from not only health care providers, but from people in leadership positions."

System lack of knowledge of population-specific medical issues

"Under 'lack of knowledge' it wasn't just culturally, it was that basically our traditional western white health care does not recognize the differences in our...native bodies are built differently. We have certain enzymes, we have other things that are missing. They do not know how our bodies work, medically."

System unwilling to blend traditional remedies with western medicine

"Some of these programs, they get a special problem, are willing to pay thousands of dollars to get a doctor to come in from John Hopkins University to go over things. Why can't they set aside a little bit of money to bring in a medicine man. A lot of people won't accept the medicine they use in these hospitals, but traditional medicine they will."

System does not recognize or incorporate consumers' health abilities

"That's part of the barrier, the distrust...that lack of respect for our own health care knowledge, that our ancestors, our culture actually did know how to solve blood-sugar problems. They HAD that knowledge, but that knowledge was considered as garbage." "The other side needs to realize that we DO have some knowledge of how to take care of ourselves and incorporate it into the system."

Urban lack of availability of health care

"If other states have PHS hospitals and things, how come Salt Lake can't have one? We have enough, thousands of Indians here....The bottom line is we need a PHS hospital. All the other tribes have it except us."

"I know that a lot of people travel to get medical care too, because they don't have the funds to do that here, so the cost is very prohibitive."

Traditional remedies

"We rely on traditional remedies more than Utah health system."

Rely on family

"We rely on family for health advice more than the Utah health system. We're family oriented."

Prevention

"A long time ago, my father used to get me up early to do my chores and to drink certain teas and take herbs to stay healthy....That teaching is no longer here. We don't teach our children [those things] any more, at least not in the urban."

"We rely more on white man's medicine, but those things have side effects that do more harm to our bodies....I think our bodies were made to be different."

"We don't tell our kids to drink water either. My grandmother used to tell us that, when we were kids, and now I hear my granddaughter say, 'Gee, I haven't drunk water in six months!' They think its funny, and I laugh too."

"We neglect dental, hearing, eyes, and low-level pain."

Urban consumer lack of family/community support

"Living in an urban area is completely different than living on the reservation. When I lived on the reservation, walk two miles, there's your family, there's your aunt and uncle. But here, you don't have that close community."

Asian American

Cost issues

"The HMO is very good for people who can afford it. I work with others at the restaurant who are trying to raise a family by washing dishes. These guys can't afford that kind of insurance but they are the ones who would get more out of it than myself."

"If it were more affordable and maintenance premiums weren't so high, that wouldn't figure much in the family budget. But we use a significant portion of the family's budget for insurance."

The high cost of insurance makes it difficult for us to do anything....I try to save in other areas but I find that coupon clipping and cutting down on utilities does little to the cost of our medicine.

Mr. M feels fortunate to have his retirement health package: "There are many others who only have Medicare and Social Security to help them out. I sure feel sorry for them. I wish there was some way to help those people."

"I don't understand why they have all these HMOs. I think all they want to do is make money. If I know I have a broken leg, I go see a bone doctor. I don't think I need by regular doctor to tell me if I need to see a bone doctor."

Home remedies

I use a lot of home remedies and have always taken real good care of myself, but still got a stroke. I still [purchase] many mail order pills, vitamins, over-the-counter remedies and grow Aloe Vera for medicinal purposes.

"I usually wait and Gaman [Japanese for 'try to be tolerant of your ailments'] until it gets so I can't sleep or do anything. Then I'll call someone to see if I should go."

My grandfather will not seek relief in any case. He is "stubborn" and will "gut it out" before seeking relief from either traditional or western medicine.

Inadequate/poor treatment

Sometimes the health care provider does not seek further diagnostic tests unless Mrs. O's daughter "consults" with the provider or asks for a second opinion.

After a lengthy and somewhat argumentative discussion with the receptionist, my mother, who speaks with an accent but is not difficult to understand, overheard the receptionist remark to the nurse "Why don't these people learn to speak English? They ought to go back to their own country!" She said "People at the doctor's office treat me like a criminal. They grab me by the arm and shove me around. They tell me to sit here or there." She utilizes traditional medicine and will exhaust that medicine until she cannot derive any relief. Only then does she seek the help of modern medicine.

My mother's use of English is limited so I interpret for her. I get frustrated because everyone from the receptionist to the doctor asks the same questions. My mother has to tell her story to everyone, even the receptionist. I mean, why is everyone asking the same questions? I get frustrated and think that they don't believe her or they can't understand her. They even treat her with a little contempt in my opinion.

I told the doctor, through my daughter, that I was getting dizzy from the increase in potassium...and told him the nurse had said to cut the pill in half. [Later] he hurried and wrote another prescription...asked a few questions and left. The prescription was for double the dosage. I don't trust the doctor now and will try to look for another but may be hopeless....When we went to the pharmacy....I wanted to tell her that [the pills] were too big for me to swallow. She did not act good. I am embarrassed when I go to the counter and the helpers cannot understand me. The way they talk to me makes me feel stupid. They talk to me like a child.

A 52 year old professional says he has had no problems with health workers.

Paperwork

"I really have problems with all the paperwork to get even one shot. I don't understand it; all that technical mumbo-jumbo.

Language and diversity

A lot of problems deal with language proficiency; the proficiency of the patient and the proficiency of the medical personnel.

Their [medical personnel] lack of understanding in the diversity issues drives a wedge between treating patients and delivering quality health care.

[A Chinese participant with a heavy English accent] says when she goes to the clinic, people treat her as if she were a child because, she says, her heavy accent makes people think she is stupid.

They don't realize that I can understand English, but have difficulty when they talk medicine [technical jargon].

"It's the issues of diversity in this state. Just because your hair and skin color are different or even if your clothes are different, you are made to feel stupid, embarrassed. Nurses, doctors, even secretaries will try to intimidate you. It can be proved by watching them talking to a minority and then a white person. The ORDER minorities to do things -- like pointing and saying 'Sit here.' -- and ASK the white patients to do the same things by offering them a seat. People think we're stupid because you can't speak English as well as them. I think it's so embarrassing when they ask if you can pay for the service when they don't ask anyone else."

[A Chinese American professional] who is married to a Caucasian has not had any difficulties with doctors, nurses, or other health care providers during her stay in Utah. She has observed, however, a unique phenomenon occurring in Utah where Asian American parents take their children in with them to "decipher the technical jargon of health care providers."

Participants agreed that "everyone who has anything to do with a clinic, doctor's office, hospital, HMO, insurance, etc. must be mandated to receive diversity training." Simply understanding that people are different is not enough. Health care professionals need training to work with non-English speaking people no matter what their culture or racial background may be. Everyone agreed that language proficiency and understanding what the responses mean culturally has a great impact on the communication between provider and patient.

Southeast Asian Americans

Costs

With new immigration laws people do not qualify for medical care.

[There was a lot of concern from the group that doctors are only there to get money. They make people sit and wait, then do a lot of tests for nothing other than dollars.]

Feel that if they are Medicaid patient, doctor wants them to come in a lot so he can get more money from the government.

At a dental appointment, one participant felt unsure about the treatment and thought the procedure was not good. The dentist then had the patient return nine times just to fix one problem, and then the dentist extracted all of the patient's teeth.

They only ask you "How you feel" and the visit does not seem beneficial.

"Does the government know where the money goes?"

Discrimination

Half of group participants raised hands that there are problems with discrimination.

At a dental appointment a woman waited 90 minutes and then an American who arrived after her payed for her appointment with cash and was seen first. That gave the woman the feeling that they felt as though she was on welfare or did not have insurance.

One man tried to go in to make an appointment only to be told to 'Go home and call for appointment.'

There is reverse discrimination from those who have achieved and have high expectations of others.

Distrust

We do not trust health system.

Same age provider is important; if provider is young, not respected

Comfort/Communication

We used to go the base hospital, but my mother became uncomfortable with the military physicians. Now we go to a private physician in the city.

People are not taught names of medication.

Diversity

Diversity by wave of immigration is very important to understand health issues of an individual.

System is one-size-fits-all, and does not meet diverse needs.

Koreans and Japanese are usually students here and operate at a higher level. Cambodians and Laotians are often refugees with little assertiveness. North Vietnamese are diplomatic and may not speak the exact truth; Southerners say things as they are.

Delay access/Low utilization

We don't get prescriptions [treatments], so why go?

Access is frustrating, time consuming, degrading; we are used to immediate access.

It is a waste of time, several hours getting to and waiting at appointment.

Don't get anything out of check-ups.

Language, lack of information, cultural familiarity, interest in patient, and confidence in doctor are all issues leading to low utilization compared to high need.

Provider insensitivity

It is easier to mistreat people who are not assertive; providers need to remind selves of this.

We get strong doses of medicine in native land, and will have already tried strongest over-the-counter medicines and expect something stronger from U.S. doctor; when doctor refuses by saying 'You don't need it' he is seen as uncaring.

It is easier to open up to a provider not of same ethnicity; Privacy and confidentiality and limited services are a greater concern than whether provider is of same ethnic origin. We feel shame going to same culture about sensitive problem; we fear judgement and feel uncomfortable.

Not giving personal advice is seen as not caring about the patient.

Expectation of doctor is as healer, attending to the whole person, asking questions about life rather than focusing only on immediate symptoms.

Taking off clothes for exam is not O.K.; it is foreign to us.

Long waiting periods

In dental office you wait longer in the office and two years for an appointment. It took two years to complete dental check-up.

There is a lot of waiting and very little examining, and you still need to wade through the paperwork and pay the co-pay.

A man had an appointment for surgery; the office let him wait in the office for three hours, then he was questioned 'Why are you here?' then the doctor told him that 'He should have an interpreter with him.'

Offices think that you are on Medicaid, so you don't get priority.

"Come on time, you wait; if late, then they don't treat us."

Language

Language barriers lead to many problems, including lack of compliance, insurance information not communicated accurately; we have been ignored because system personnel thought we cannot speak English.

Can't get an appointment without help, so problems arise if an emergency comes up.

Doctor delayed surgery for three hours because doctor says he needs an interpreter first.

Paperwork is a problem.

Lack of speaking English creates a problem, mistakes in paperwork can lead to problem.

No office provides interpreters, so you have to use a neighbor or friend. They aren't always good.

There is a definite need for interpreters at Refugee Center.

[Communication] problems are with both sides, the staff as well as the patient.

Three-quarters of group participants raised hands that they had experienced problems and misunderstandings in the clinic.

Written translations in pamphlets, for example, "Turn my face red" and make me feel like "They really look down on my language." This does more harm than good. Respect for culture is a big issue. Translations must be accurate and in the proper cultural context.

Interpreters

The problem is interpreters are not accessible, we have to rely on neighbor, friend, or children.

When we ask for interpreter service, it is not available.

When they do use an interpreter, they don't know if they have done a good job.

One man who helps the refugee families said there is only one interpreter at the New Hope Refugee Center -- only one social worker -- and they need interpreters; very important.

Transportation

Sometimes it is hard to find transportation, so appointments get missed. Half of group participants raised hands that they had missed appointments due to transportation problems.

Problems with going back and forth for health troubles; the whole family has to work to get transportation handled.

Most elderly cannot make appointments without help.

A participant had a physical therapy appointment and showed up late because they got lost; "Rather than try to fit her in, they refused her service."

If we come late, we get no service.

Traditional remedies

Almost all people said they use traditional remedies rather than go to the doctor.

Will try home remedies unless a major problem.

Most doctors are only concerned about how the injury occurred, not about what patient has already done with traditional remedies.

There is a concern with the doctor noticing, such as a scratch on the arm from remedies, and accusing husband/father of physical abuse.

Gender issues

Here, the shift of power to women here is "like an earthquake" and no family counseling resources are available to address this.

Touching is easier if provider is of same gender.

Compliance

Some said that they follow doctor's orders, such as with prescriptions, but some stop when they begin to feel better.

Appointment breaking, being late is part of survival strategies from old home. Providers need to understand this.

Concept of dosage: If a little is good for you, then more will be better.

There is a lot of sharing of medicines in family.

Continuity of care

Follow-up is difficult due to high mobility; continuity of care is very difficult.

Prevention

[The group's concept of prevention is 'going to the doctor for check-up' -- no western concept of self-help to prevent disease.]

Health for us is subtle, less direct than muscles, sweat, and Diet Coke [as in U.S.]; it's a balance between yin and yang.

In Southeast Asia, there is no prenatal care, childbirth is a natural process using yin-yang principles; fruit is not eaten [during pregnancy] to avoid parasites; beer is thought to be good for baby. These practices are carried over here.

This was the first time they had heard about such a thing as prevention [other than government public health prevention programs such as welfare, WIC or immunizations] They do have an annual health fair at the New Hope Refugee Center.

Nearly all said that prevention is important. Know that they need to teach good health.

Many feel that if nothing is wrong, they do not need 'check-up.'

Prevention is important, but they need to know where and how to access; need public communication specific to their needs [for example, immunizations].

Approximately half raised hands that they [a significant number are elderly] don't get regular check-ups due to troubles with cost, access and comfort with health system.

"Never before been able to discuss prevention." [When asked if they utilize government prevention programs.]

There is a "knowledge deficit," a lack of information; a clash between previous and U.S. system. We need education in western medicine. We need to learn assertiveness.

We are adopting U.S. lifestyles such as drugs and alcohol to cope with stress.

Latino/Hispanic/Chicano

Cost issues

"These people are barely surviving, to go out and pay \$50.00 for something, a health procedure, doesn't make sense to them."

"If they don't have money, they try anything to avoid the bill."

"I had a client who was pregnant, she didn't know what to do. She didn't want to get anything from the government [financial aid], so she didn't go to the doctor. The baby died in her tummy. She thought she was six months pregnant, the baby had been dead three months. It turned out to be a lot more money."

"Women do not feel to go to the clinic because these are very expensive. Taking into consideration that Latinos belong to among the poorest ethnic group in the USA, clinics need to be able to provide them with installments so that Latinos could compromise to pay the bills. Latinos would be more than willing to commit their selves to a debt."

Lack of information about health system

"The second issue is the lack of information about the eligibility to get health services: Who are entitled to receive services in the USA? What is the difference between a legal resident alien, an American Citizen, and an undocumented individual?"

Traditional remedies

"They don't delay medical care, they come in having already approached it in their own way; not with the western medicine."

"When a Latino gets to a health care system, it is because he or she has already tried several home remedies, some medicine that someone had given him, and the questions are not even asked; what remedies have been tried?"

Need to address gender differences

"The issue of gender must be addressed, women and men in all cultures are treated differently and the Latino culture is no exception. I have seen women become more trustworthy of women even if they are not doctors than of male doctors; and a lot of that has to do with the fact that women treat women with a more humane and caring way than men. Women are less condescending, less patronizing."

"Women have a tendency to use the same terminology that makes us comfortable; we know the same words, we use the same terms."

Women feel more comfortable with female doctors. They must be able to select a female doctor.

Provider insensitivity

Receptionists are very rude.

Distrust comes from lack of caring.

"The system is racist through and through, so even acculturated [Latino] 'Americans' treat other Latinos poorly."

"Doctors have a tendency to depersonalize everything because of the science versus everything else. There is a need for doctors and staff to be acculturated and more humanistic, and show sensitivity for diverse cultures."

"People who don't understand a person's culture or language are very impatient."

Doctors and staff need to be acculturated/human.

Perceptions of health

"Pregnancy is seen in Mexico as a healthy process of life. You come here and its an illness and you have to go see a doctor right away."

"What do Latinos mean with health? Pregnancy among Latinos is considered as a normal process in life; it is a blessing, while in the USA it is viewed as a medical condition."

"An illness could be viewed as a punishment, and as a result the sickness is in the hands of God."

Family orientation

"We are taught in the religion, take care of your familia. The Latino familia has always been strong, but lately the familia has been deteriorating and I hate to say its because the Anglos have put that in our minds."

"We don't neglect our elders like they do here; we take care of them 'till the day they die."

Taking the elderly to a care home would be considered as abandonment, because their religion, some of them, says that the family needs to take care of their family.

Diversity within culture

"We have a lot of our people that don't have that; a solid foundation of culture. We have a variety of cultures. This makes it very difficult when we try to get across a system which is number one, too costly, and number two, racist. How we dress makes a difference in how we get treated. If I wear a suit I get treated differently than if I dress how I am now. Its a disrespect of our culture."

On the other hand there is not just one Hispanic culture, but a diversity, among newcomers and families that have lived in the USA for several generations.

System insensitivity to human concerns

"The first question we ask is 'Do you have a card?' 'Are you legal?' Not 'Are you human?'"

Latinos in general are not treated well, treated with rudeness. The cultural differences and language barrier are a real obstacle giving room to plenty of stress. The rudeness contributes to anxiety and as a consequence the Latino people isolate from reality.

The way that Latinos are treated by health providers does not conform to the cultural standards that they bring from their home countries.

Continuity of care

There is no continuity between doctors and patient. If a Latino patient comes to a clinic to receive medical care, the next time she/he comes to the same clinic a different doctor will be in service. This situation contradicts the Latino view of health care. For them a doctor is a very special individual that has the patient's life in charge. Somebody who they have placed all their trust, and somebody that could not be changed easily. The relationship between the physician and client is very important.

Respect for culture

"Anglos tend to depersonalize things because of a science versus nature attitude."

Consumer knowledge about illness and disease

"We need more information about what is happening in our culture"

Lack of access to doctors/Inadequate community clinics

"We need more clinics because the ones that we have are so full we have clients waiting a month for prenatal care."

Language

"[In relation to translation], you are going to have to consult a variety of us because the same issues of nomenclature appear in our language."

"The first issue is the language barrier -- conforming with the opinion of diverse health providers. The problem exists."

"A gentleman came to visit his daughter to the States. One evening the daughter asked her dad to go out and buy some tortillas. The father got lost and nobody could find him that night; later he was found in a clinic for mental illness. He remained in this hospital for three years. This example shows that the language barrier could destroy life."

"When there is not quality communication, there is no quality service in health care provider."

Prevention

Among Latinos, there are many that do not accept the concept of prevention, but face the reality; an illness could be viewed as a punishment, and as a result the sickness is in the hands of God.

Among Latinos there could be priorities that could come before the health issue, such as food and shelter. Poverty is an important factor in health. People who are getting a poor nutrition, junk food, are more susceptible to get diseases. Families living in overcrowded houses are also [more] susceptible to diseases. Prevention has a direct correlation to socioeconomic factors.

Health in a culture of poverty is different. In Mexico if you are poor, fruits and vegetables are available, but not here...It's drugs here.

"Prevention is education. Educate Hispanics about what there is available."

"Hispanics don't neglect prevention, they may lack the education or access to health care; they take care of their own."

We do not believe that Latinos neglect health care and prevention, we rather say that they do not have the education and information about the diverse health services in the country. In fact, they care about themselves.

Seasonal Farm Workers and Recent Mexican American Immigrants

Health system does not serve needy

Unjust opinions of undocumented

Fear accessing because of personal information

Do not access prenatal, vaccinations, early disease processes

Wait too long until very ill when finally go to the ER

Stressful lives, causing family break-up, unsupervised kids; tremendous mental health need

By the time access, they've already tried a lot themselves; many remedies, asked people. Docs need to first ask "What have you done about this?"

Only way to access is through "trust chain;" a personal bond with M.D.

Whole system is strange, foreign, "its out to get them", not very inviting

Providers don't want to treat them, people feel this immediately

Without trust information not given, don't tell doc the whole story, resulting in wrong diagnosis

Provider does not communicate with patient, even after surgery, patients don't know what happened!

Human, cultural barrier even more of a problem than language

Its more important provider cares, than his "broken Spanish."

For sliding scale clinics, asking personal income questions, people distrust and give inaccurate information

This paranoia is very dangerous, they take this very personally, overreact

Survey: Go to people who have trusting relationship with population, priests, people do open up to them

Everybody uses them, they are part of U.S. economic system, but when it comes time to provide services, U.S. turns back, not treated as human beings. If they were not here, the system would have to make up for that, who will work their jobs? Need to legitimize their position, make them visible first.

Use source of jobs (farms; pig in St. George, turkey in Ephriam) and churches to identify population/ sample

Biggest issue is social, not medical, but ends up being health issue

Their human rights are minimal, they are not expecting to be put on welfare, but need health care, mostly preventative

Don't know availability, do not know where to go

Low income, no insurance

Transportation - family has single car for father/worker, Latino/Hispanic women do not drive because of culture

Language a barrier, don't know how to access

Distrust - white providers don't know us -- our problems

Self-remedy from Mexico rather than seek U.S. care

Translators only available for paperwork, miscommunications/misinterpretations about symptoms and instructions, translation a low priority

Survey: food is always an attractor, incentive, child care should be available, depends on time of day, not at dinner time, lunchtime

Expected to wait 2 months for prenatal care visit at Central City, prenatal care not common in Mexico

Treated coldly and rudely or not with respect at clinics, need services but won't return for more rudeness, Shouting across crowded waiting room "Can you pay for

this?" "This great prejudice" also exhibited by 3rd & 4th generation, and South Americans as "superior"

Latino community does not believe in mental health counseling

Gender barrier for women

WIC video not really learning anything but do to get voucher, going through motions, class not offering much

Use established relationship and trust system to bring together. Group facilitator age or race not an issue but someone you'd feel comfortable with

Show attempt to integrate some of their culture and then "maybe I will too."

Differences between South American and Central/Mexican

Latinos "would rather go to a place where they don't speak Spanish, but where I feel they treat me like a human being."

Providers do not accept or incorporate "healers" which causes additional problems for Latinos

In general, tend to ignore minor symptoms and relatively minor injuries, have a more holistic approach to the world, so health is much more "natural." More natural childbirth among 1st generation Latinas because pain is seen as a part of life.

Relinquish control when major health problems arise, because its "God's will" that this happened, great impact on willingness to follow instructions, work with physical therapist, for example.

Increase Latino's understanding about their role as consumers of American health care and promotion services; address strong stigma against mental health care

Recognize and act upon strong family-oriented social structure

Cross-culturally appropriate training for all parties

May be difficult to get them to participate in group sessions

Prevention - talk about safety and health, rather than physical and sexual abuse, will be accepted then, "It is unsafe to strike someone, it is unhealthy to abuse someone sexually."

Survey: will not be responsive to written, or abstract, telephone communications or survey administration methods, use churches other culturally-specific community organizations and respected community members to obtain access to and meaningful participation. These organizations & individuals can give the message that participation in the survey is OK, and that it is safe to do so. Assure that it is a survey not representatives of government organizations with hidden motives for contacting or identifying

Mistrust of this process, "we've done this already;" they are frustrated that we are holding at the beginning stages of change

Division of Mental Health has been "out of step" but becoming interested in ethnic health issues

*Medical competence may be more important than care from "one of our own."
Paraprofessionals do not fully fill the gap in services*

Latinos tend to use what is available to them, to take care of self first

Diversity in acculturation needs to be addressed in planning and providing services. Diversity between acculturated and newly arrived important to recognize and address

Clear differences in Latino gender roles, mother can't change diet without the change being accepted by the father, so classes for mother will do no good without attention to father

Personal relationship important for them to return/continue treatment. Client oriented services, "personalismo;" honoring the principle of starting where the client is key to encouraging appropriate access and follow through

Most Latinos believe in alternative treatments and religion in health. They will talk to their priest first or deal with health problems within family before accessing services. They will ask or listen to a relative in matters of health. The family is trusted and relied upon

Survey: letters don't work with Latinos because they are seen as too impersonal, stimulating questions of "what's in it for me" and suspicion. Same for phone contacts. Use a personal reference to set appointment to see personally. Latinos willing to talk about personal health if can minimize natural suspicion and fear of being used. Questions should be clear and asked in a direct manner. Assure information will be used to resolve problems and initiate more personal and relevant services

Translators should be certified by the state

If [you] can highlight link to legislature that they are impacted -- that T.B. is a public health issue; that is the only arrangement that works

Pacific Islander

Lack of recognition, acceptance and respect for diversity in culture

"Our main issue we came up with is the lack of recognition and respect for diversity in our culture."

Cost issues

"Insurance, cost of health care...it is number one. It's related to access because if you don't have the money...."

"They won't take you if you don't have insurance."

"A lot of this is financial."

Access

"We do have illegal alien, elderlies, and some young too, that have health problems that do not have access to any health [care] because of their status."

"We probably don't know what's available out there. The technical language is difficult to understand and sometimes we have pride and we won't ask."

Insensitive providers

"Providers are clumsy [in dealing with people of different ethnic populations]."

The environment is artificial...sterile, not comfortable for our culture.

We need a pool, a directory or coalition, of our own people in the medical field to help with the system.

Consumers delay access to system

"People wait too long to access the system [because of] cost, fears, language, hidden agendas that are not spoken, coming from underneath the system. For example, when I go to Nordstrom's to return an item, I have to present two identifications to state why I am returning this item. The person in front of me and in back of me does not present two identifications"

Language

"I think we should be sensitive to language. We need translators, especially to get representation of our elder population."

"Translators need to be paid. A lot of our people are always asked to do things for free and that's why I really appreciate what you guys are doing today. Translators need to be compensated."

Family involvement

"My grandmother was just in the hospital recently and the whole extended family wanted to go, and constantly they would tell us 'There's only to be one or two in the room.' That's a conflict of how we define space. The health system would say only two people can fit in this room and the Polynesian think ten people can fit. And, because extended family is so important, sometimes there is conflict with [the] system because of values are different."

"When our mom is sick or when our auntie is sick and you're not there it shows you don't love them, you don't respect them, you don't care. So, everyone is there."

"Does the system create the rules? You betcha. Can the system change those rules and policy? You betcha. Family or your support system...is a very important part of the healing process. As a nurse, I say we can create the rules."

"We value our families and the system thinks the less people, the less interruptions."

"Here's what happened in one hospital in California. There were about 30 to 40 of us. They came and said 'We know your auntie is very special, important to you. But if you will just stay in this room and then have two go in to see her....' The asked us to help."

Herbal medicines

"I don't know how the system feels about our people coming in and using their herbal medicine. They should address it. I don't know where they stand on it. My incident was not an isolated one."

"The medical people, doctors and nurses, should be open, not believe in it, but accept."

Mental health

Mental health is not discussed, it's a cultural taboo, no language in our culture to describe mental disability.

Mental stress is not addressed.

Prevention

"It seems to me that we also have to recognize and accept the health care system for the sake of life."

"Educate, educate, educate."

"Pride doesn't allow them to get welfare, which would free up some time to exercise and give them access to healthy food."

"A lot of older people would rather eat the foods they're used to and be happy than prevent themselves from getting diabetes, high blood pressure and things. The

health care people don't understand the types of food we eat, and economics and exercise."

"Meat is like candy...a treat in our old home. So now it is plentiful [in the U.S.]... [and] we eat a lot of meat."

"A lot off things are geared to other cultures, like my kids are naturally big and they tell me 'your child is too big.' Educate the health worker towards our culture."

"The health approach is very ethnocentric [word used and defined by facilitator during discussions], meaning everybody is judged by one perspective, like meet the scale for the average white person."

Give us a substitute to the habit, don't just tell us to change.

Follow through to re-motivate; a one-time health session won't do.

"We [more acculturated persons] speak up so we don't feel it, but we felt there is discrimination out there. [They] don't spend time talking to our people to find out background of the issue. They'll say 'Well, she's brown, maybe she won't understand."

"We just enjoy, don't really have prevention mode per se. We don't even have the word 'prevention' in our language." "I think that can be traced back to our not fear of death and our not fear of age, which I think is a very cultural thing. In fact, as we age, we look to age as wise, the leaders of family, etc."

Their diet is very high in fat and starch, but people would rather eat what they want and risk diabetes.

Health people don't understand what Pacific Islanders eat.

"The bottom line is eat what we eat and die young. [Prevention] is just not in our thinking."

"There is no time to exercise because they work so much."

"I'd rather use the word 'education' not 'prevention,' because we are educating from this mode to this mode. 'Educate' makes sense, 'prevention' doesn't."

The system needs to be educated about standards of the culture; the weight and height of Pacific Islanders is different than for Americans. Need to take this into consideration.

"In the islands we had a certain diet; but to fix the food they had to climb the mountains, climb the trees, bring it down, fix the fire, all exercise in itself. They ate heavily but it all burned off, and people walked everywhere."

"You have to show [the information]. They are right-brained people. Its a visual thing."

We learn by doing, so written information or cognitive presentations will not be very successful.

"I think they need to identify with how it was back in the Islands and how it is now....Your mountain climbing and doing the fire would equal to one hour of aerobics. [Use this example as] kind of like a comparison so they can really identify with the problem, see where they were, where they are now, and the alternatives."

"Education needs to be continuous, consistent because motivation lasts as long as a bath; and the best way to do that is through the religious community."

[End of health and prevention issues comments]

RESULTS (continued)

DATA COLLECTION STRATEGIES

African American / Black American

"Surveys go into the trash."

"You figure it is a solicitation for funds, a solicitation for something you're probably not interested in so you throw it away."

"It is not guaranteed to get any attention."

"There is the hopelessness of another governmental survey. Many feel this already has been done and nothing has come of it so far, so, 'Why should I participate again.'"

Unless participants can be assured that their participation will be of value, even enticements such as payment or food for their participation, will be of no avail.

Some community leaders are threatened by the survey, feeling that their organization was already involved in a program to help improve the health care for Blacks. This led to disinvolvement of those members of [my] organization who had made an earlier commitment to participate in the survey.

"The approach used to conduct [this] survey is a good approach. You talk to people one-on-one. You have people of color talking to their own race. That is a good and positive thing."

"You need to contact community leaders because they are the ones who meet and discuss what is going on in their community. You need to contact the consumers - go to a clinic or some place -- and sit and talk with the people."

In the Black community there exists a great deal of fragmentation. There is lacking a sense of cohesiveness. Until this is addressed, programs which can benefit the community as a whole will go by the wayside.

Don't make it long, so it only takes a few minutes.

The community should be involved in the planning process; networking system.

"You don't have time, and then when you have people asking a lot of personal questions and you don't know who is on the other end of the line. Why would you wanna answer these questions?"

"The best thing you can do with a phone call is probably set up an appointment to go see them face-to-face. That's probably the best thing you can do for them."

"The best way to do it is have someone from the population from the community, members of the community if you will come door-to-door, church-to-church, go to the people where they are, spend time with them and get surveys."

"We have avenues to do it well, if you tap those kinda connections you can get one good survey result. It can happen."

"If you get to these people, these are people who you can identify with. Get to the person who is the head of the [organization] and you say to them this is a survey for your community. Then they can in turn communicate with the people in that group because that's who they identify with."

American Indian

"The best way to get Indian people is food!"

"I think the most important part of gaining access and participation is having Indian people do the survey."

"Survey itself represented distrust. It's a word that implies meddling, digging into somebody else's business. So, changing the word.... We need to find a better word than survey."

"Using a facility where people feel comfortable, some acceptance."

"Look at population level. Don't use \$50.00 words. Whoever does it is at the level of the people they're talking to."

"Sometimes they go in there and they're time limited and try to get those questions out fast. A lot of cultures, you have to sit down and talk with them about whatever, eat or drink."

"People need to understand that when people nod their heads it's not necessarily yes. A lot of the elders, when they're listening, they'll nod their heads 'Yes I'm hearing you.' not necessarily 'Yes, I agree with you.' The respect your comment."

"We, as Indian people need to be active [to get things done]."

"It's our problem, but [some say] 'they' should fix it. I'm going to stay home and watch TV."

"Phones are so impersonal."

"I think we've just touched on the surface of health issues, mental health, substance abuse. I'd like to see a group like this continue. These issues are really important and we're not going to get anything unless we come together and keep saying this is what we need, this is what we need."

"I think it's important to review the questionnaire or whatever you call it, so that we can say 'Yes, this is a good way to say it.' or 'No, this is not a good way to say it.'"

Asian Americans

"Phone survey is a problem with language."

"[Need] more discussions like this."

"They are willing to do mail survey if the return/postage are included."

"Language is a problem with surveys. Send information to a community leader to distribute."

"Governor Leavitt is a good guy, but needs to talk to minority people. Ethnic committee should act as a liaison, report back to government."

Survey incentives will increase accuracy of information provided: "You will get good information if you pay."

The population moves slowly and trust and rapport must be built first. Have someone who is known to population involved, someone they trust to do survey. Ensure anonymity. We will give you what we think you want to hear, fearing [you] are like communists who will turn against us. "In my culture, it is tradition not to speak your mind." It is rude, you have to say things to please others. Yes/No questions don't work in this culture. Double negatives are a problem. When Asians shake their heads "Yes" means that they are paying attention. It is rude to shake the head "No."

Latino/Hispanic/Chicano

"When you say the governor wants to do a survey but we have it going through the legislature that any document has to be in English. How are you going to get the survey through?"

Instrument has to be really good [clarity, language].

Needs to be done in both languages side-by-side so that the translator/surveyor can see both to make it clear to Spanish speaking.

"It's going to be costly to be well done."

Sample needs to be well-defined [to address diversity and representativeness].

"Every culture has gatekeepers. Organizations like Centro. We have workers, staff, that has developed a rapport with families over a period of time. You come and convince me that it is a good thing and I will help you convince my staff and in turn they will get the information from the families. It is a long process."

It doesn't matter what ethnicity the surveyor is, as long as the person is sensitive and caring, well-trained.

Advertise survey using the press in the language of the ethnic group; Latino newspaper.

Pacific Islander American

"A lot of the government like to use the church groups to get their information, but...that is a problem because a lot of the people, when they go to church it's a spiritual thing and to get up and say something that is out of the spiritual context it is a difficult thing for them."

"With other churches, this is the only way to communicate...to go through the church....We still make the contact to our people stressing the importance of [something like this]."

"If it is something to help the members, then it's O.K. to go to the leaders. Maybe do after church or something else. If good for the ward, too [then it's O.K.]. I think the only way to go about it is the wards."

"It's the very first thing that Polynesians think of. If you want something done you go to the churches because that's where the main group is. And, we are so attached to our religion, whatever religion it may be. That's the center of our life."

"Perhaps the community organization is the way to go. There are many different Polynesian community organizations that could push these surveys."

You have to develop trust.

"In order to develop the trust amongst the system and the Polynesian people...some of our people have experienced that the government says one thing and when they go to access that it is doing another thing."

It is important for people to understand how information will be used; confidentiality is important to understand how it will be maintained. Community organizations are important to this process.

"Representation while doing the survey is a very important factor here. For example, if we were to go out and do a survey with Polynesian people, it is important that we have Polynesian people with us because if I were to look out at these survey takers and...there were no Polynesians, [then] I don't know if what I am saying is going to be understood."

"If the community organizations were used, along with the expertise of the Health Department and the University of Utah combined, it would be very strong in reaping these surveys, or this data we are looking for."

"We need to stress the importance of how this was going to benefit our community and I guess maybe it's like a selling job that we need to do. Even though it's for our own benefit, some of our people, there are so many things going on in their lives, that sometimes we have to sell to them that this is really important."

"Paying money to organizations was another suggestion [to get survey done]. Giving them some kind of money to do this. Such as Cricket organization...donate money to their organization."

There are Tongan physicians, P.A.'s, nurse practitioners, registered nurses out there that our community doesn't know about, or have the access to, and they would be more than happy to help out. Create a pool system; develop a network, an Polynesian medical profession network or something like that."

"Also, a lot of our people are in community centers. Maybe that is another way of doing the survey."

"I think we should be sensitive to language. We need translators, especially to get representation from our elder population."

"I feel there has been a lack of education and communication with Polynesian people in the community and I just feel strongly that we need to educated our people on what is going on and keep them informed. There's a lot of things out there for them."

"We would like to do a comprehensive survey...health, workforce, education and go to the people only once. We can't bother people."

"The way you are conducting the survey is the way it should be done."

OVERALL SYNTHESIS OF FINDINGS

This study was designed to bridge the gap in understanding about health issues that are important to ethnic populations, and to suggest strategies for successfully collecting health-related information among Utah's ethnic populations. We adopted an open, inclusive qualitative approach to give voice to a diversity of ethnic population members in discussing these issues and suggestions. This study represents only a first step among several toward encouraging ongoing and productive dialog among health system service providers and consumers, about the nature and extent of health services and activities affecting Utah's ethnic populations.

The following were the major health issues voiced and discussed by Utah's ethnic populations during Summer, 1997:

***Payment for Health System
Services
Human Caring and Respect
Respect for Culture
Cultural Competence
Access to Services***

***Accessing Services
Traditional Remedies
Distrust of System
Language
Transportation
Prevention***

Each of these issues is *summarized* below with selected quotes from study participants intended to *illustrate* an issue, not necessarily to define it. For more depth of understanding, we recommend consulting the quotes and statements presented in the results section of this report. Study findings related to health data collection strategies are not further synthesized here but are incorporated into a separate report designed to guide planning and completion of the larger quantitative ethnic health survey planned for 1998.

Payment for Health System Services

African American / Black American

"Medical care is so expensive that old folks and poor folks cannot afford it."

American Indian

"Indians feel shame when they cannot provide for their families."

Asian American

"The high cost of insurance makes it difficult for us to do anything."

Southeast Asian American

"With new immigration laws, people do not qualify for medical care."

Latino/Hispanic/Chicano

"If they don't have the money, they will try anything [at home] to avoid the bill."

Seasonal Farm Worker

"The health system [as a whole] does not serve the needy."

Pacific Islander

"Insurance, cost of health care -- it is number one."

Human Caring and Respect

African American / Black American

"It seems that when African Americans go to the doctor's office they will serve all the whites first...even if the patient is on time...[they] make [you] wait."

American Indian

"The attitude among rural providers is that American Indians do not deserve equal health treatment due only to being American Indian."

Asian American

"[A patient overheard a receptionist say to a nurse] Why don't these people learn to speak English? They ought to go back to their own country!"

Southeast Asian American

"There is [also] reverse discrimination from those who have achieved and have high expectations of others."

Latino/Hispanic/Chicano

"The system is racist through and through, so even acculturated 'Americans' treat other Latinos poorly."

Seasonal Farm Worker

"Providers don't want to treat them; people feel this immediately."

Pacific Islander

"The environment is artificial, sterile, not comfortable for our culture."

Respect for Culture

African American / Black American

"You can tell by the doctor's body language if he is relaxed or uptight."

American Indian

"Traditional values:The white doctors or nurses need to be trained to understand or recognize these values."

Asian American

"It's the issue of diversity in this state. Just because your hair and skin color are different...Nurses, doctors, even secretaries will try to intimidate you."

Southeast Asian American

Diversity by wave of immigration is very important to understand health issues of an individual.

Latino/Hispanic/Chicano

"There is a need for doctors and staff to be acculturated and more humanistic, and show sensitivity for diverse cultures."

Seasonal Farm Worker

"There is an 'air' about [clinic staff] that [workers] will go to WIC office to ask them to tell the clinic they're here for their [clinic] appointment."

Pacific Islander

"Our main issue...is the lack of recognition and respect for diversity in our culture"

Cultural Competence

African American / Black American

"Doctors don't have enough experience to meet the needs of African Americans."

American Indian

"Medicaid workers are insensitive to Indian issues and Indian people."

Asian American

"Everyone who has anything to do with [the health system] must be mandated to receive diversity training."

Southeast Asian American

System is 'one-size-fits-all' and does not meet diverse needs.

Latino/Hispanic/Chicano

"Women feel more comfortable with female doctors. They must be able to select a female doctor."

Seasonal Farm Worker

"The only way to access is through a 'trust chain,' a personal bond with M.D."

Pacific Islander

"Providers are clumsy [in dealing with people of different ethnic populations]."

Access to Services

African American / Black American

"People still think that mental health care is only for people who are 'crazy.' She tried to explain to them that [it] covers a lot of things like depression, family matters, etc."

American Indian

It is a false assumption that all American Indians are served, and served well by the federal government: Recent IHS cutbacks and closing of SLC Indian Health Center.

Asian American

"I don't understand why they have all these HMOs. I think all the want to do is make money. If I know I have a broken leg....I don't think I need a regular doctor to tell me if I need to see a bone doctor."

Southeast Asian American

Can't get appointment without help, so problems arise if an emergency comes up.

Latino/Hispanic/Chicano

"We need more clinics because the ones that we have are so full we have clients waiting a month for prenatal care."

Seasonal Farm Worker

"The whole system is strange, foreign, 'its out to get them;' not very inviting."

Pacific Islander

"We do have a lot of [people] that have health care problems that do not have access to any health [services] because of their status."

Accessing Services

African American / Black American

"So much is that you don't feel comfortable...because you know you're going to be gawked at because you're the only Black person in the waiting room."

American Indian

"Sometimes we just need more help to get a birth certificate, know how to use insurance, apply for assistance."

Asian American

"I usually wait and Gaman [try to be tolerant of my ailments] until it gets so I can't sleep or do anything. Then I'll call someone to see if I should go."

Southeast Asian American

Access[ing services] is frustrating, time consuming, degrading; we are used to immediate access. We don't get prescriptions [treatments] so why go?

Latino/Hispanic/Chicano

"They don't delay medical care, they come in having approached it in their own way; not with western medicine."

Seasonal Farm Worker

"They can't stop working to go in; If they don't work they don't get paid."

Pacific Islander

"People wait too long to access the system [because of] cost, fears, language, hidden agendas that are not spoken, coming from underneath the system."

Traditional Remedies

African American / Black American

"I think...quite a number of our people use their own traditional means or family to try to help them to alleviate some of the suffering...rather than go to the doctor"

American Indian

"We rely on traditional remedies more than the Utah health system."

Asian American

"I use a lot of home remedies and have always taken real good care of myself."

Southeast Asian American

Almost all people said they use traditional remedies rather than go to the doctor.

Latino/Hispanic/Chicano

"When a Latino gets to a health care system, it is because he or she has already tried several home remedies...."

Seasonal Farm Worker

They self-remedy from Mexico rather than seek U.S. care.

Pacific Islander

"The medical people, doctors and nurses, should be open, not believe in it, but accept."

Distrust of System

African American / Black American

"No one believes bureaucrats. They have a credibility problem: Tuskegee, atomic testing"

American Indian

"As Native Americans we are totally mistrusting because of what has gone on with our people. We voice our opinions...but what's going to happen?....Nothing."

Asian American

"I really have problems with all the paperwork to get even one shot. I don't understand it; all that technical mumbo-jumbo."

Southeast Asian American

We do not trust the health system.

Latino/Hispanic/Chicano

"Distrust comes from lack of caring."

Seasonal Farm Worker

They [the undocumented workers] delay accessing services until they need emergency treatment because of personal information and fear of deportation.

Pacific Islander

"[There is] Distrust of haole [term for mainlander] doctors and their medicine."

Language

Asian American

"A lot of problems deal with language proficiency; the proficiency of the patient and the proficiency of the medical personnel."

Southeast Asian American

Language barriers lead to many problems, including lack of compliance, and insurance information not communicated accurately.

Latino/Hispanic/Chicano

"A gentleman came to visit his daughter to the States. One evening [she] asked her dad to go out and buy some tortillas. The father got lost and nobody could find him that night. Later, he was found in a clinic for mental illness. He remained in this hospital for three years. This example shows that the language barrier could destroy life."

Seasonal Farm Worker

Language is a barrier, they don't know how to access.

Pacific Islander

"I think we should be sensitive to language. We need translators, especially to get representation of our elder population."

Transportation

American Indian

Transportation is an issue especially for rural American Indians.

Asian American

"I take my mother to and from the doctor's office."

Southeast Asian American

Sometimes it is hard to find transportation, so appointments get missed. [Half of 35 group participants raised hands that they had missed appointments due to transportation problems.]

Prevention

African American / Black American

"I think it [prevention] needs to be more personalized in addressing [individual needs]....more geared to African Americans...FOR people, BY their culture"

[Prevention] programs and services are not visible in ethnic communities.

What tends to happen is this token type of mentality that, 'O.K., we've already funded one program that is related to that.' so they figure they are doing enough.

American Indian

"A long time ago, my father used to get me up in the morning to do my chores and to drink certain teas and take herbs to stay healthy....That teaching is no longer here. We don't teach our children [those things] any more...."

Southeast Asian American

Health for us is subtle, less direct than muscles, sweat, and Diet Coke; its a balance between yin and yang.

Many feel that if nothing is wrong, they do not need "check-up."

This was the first time they had heard about such a thing as 'prevention.' "Never before been able to discuss prevention."

Prevention (continued)

Latino/Hispanic/Chicano

Among Latinos, there are many that do not accept the concept of prevention.

"Among Latinos there could be priorities that could come before the health issue, such as food and shelter. Poverty is an important factor in health."

Pacific Islander

"We just enjoy, don't really have a prevention mode per se."

There is no time to exercise because they work so much.

"Meat is like candy...a treat in our old home. So now it is plentiful [in the U.S.]....[and] we eat a lot of meat."

"A lot of things are geared to other cultures."

"You have to show [prevention]. They are right-brained people. Its a visual thing."

We learn by doing, so written information or cognitive presentations will not be very successful.

"Give us a substitute to the habit; don't just tell us to change."

"Follow through to re-motivate; a one-time health session won't do it."

"Education needs to be continuous, consistent...motivation lasts as long as a bath."

SYNOPSIS

In this section we briefly summarize the key elements of the *Utah Qualitative Ethnic Health Study*. In the final section of the report we offer and discuss suggestions for action that are based upon study results.

Purpose

This study was designed to 1) bridge the gap in understanding about health issues that are important to ethnic populations in Utah, and 2) suggest strategies for successfully collecting health-related information among Utah's ethnic populations.

Approach

We adopted an open, inclusive qualitative approach to give voice to a broad diversity of ethnic population members in discussing health issues and suggestions for change.

Participants

More than 200 members of Utah's ethnic populations representing at least 20 separate ethnic and cultural backgrounds throughout the state participated. An even mix of health consumers, providers, and community workers from African American, American Indian, Asian American, Latino/Hispanic/Chicano, and Pacific Islander populations participated in the study.

Method

Culturally diverse community liaisons and project staff completed 57 formal personal interviews, seven population-specific group discussions and 34 additional telephone interviews throughout the state.

Validation

Participants were given several opportunities to clarify, validate and expand upon their messages during each phase of the project. To further ensure the accuracy of findings, group sessions were audio-taped.

Analysis

A final project report organizes direct quotes from participants to synthesize, *in community members' own words*, the messages they wanted the health system to hear. As a final analysis step, 48 participants were asked to validate and comment on synthesized results.

Results

The major *health issues* voiced and discussed by Utah's ethnic populations during the Summer, 1997 centered on the following:

| | | |
|---|-----------------------------|---------------------------|
| <i>Payment for Health System Services</i> | <i>Cultural Competence</i> | <i>Distrust of System</i> |
| | <i>Access to Services</i> | <i>Language</i> |
| <i>Human Caring and Respect</i> | <i>Accessing Services</i> | <i>Transportation</i> |
| <i>Respect for Culture</i> | <i>Traditional Remedies</i> | <i>Prevention</i> |

SUGGESTIONS FOR ACTION

Utah's racial and ethnic minority populations have voiced clear messages about how they and the health system can act to improve the health status of individuals within these populations. A common theme among study participants was that they want to be included in the health system, not excluded as they now feel that they are. Study participants were not demanding new or separate programs or services; they spoke of inclusionary adjustments to meet their needs.

Nevertheless, study participants expressed clear expectations that their participation in yet another study must, this time, result in timely and responsive actions from the health system. Some participants stated outright and others agreed that this would be the last time that they would participate or cooperate should the health system fail to promptly act in response to study findings. We offer the following suggestions to facilitate actions that can effectively respond to these messages, and the messages that are repeated below.

"Providers need to know something about the culture...."

"We need education in western medicine."

Suggestion 1: Build cultural and system competencies among health system providers and consumers.

The simultaneous and meaningful participation of health system providers and consumers will be required to successfully address ethnic health issues. Actions to build cultural and health system competencies will be most successful using

personalized strategies that explore the rationale or reasons for change in service provider and consumer behaviors, model the desired behaviors, encourage practice in real-life settings, and offer ongoing feedback for refinements.

Health system actions demonstrating human caring and respect, equitable treatment, appropriate services, meaningful communications, and consumer involvement in service provision are needed. The most needed consumer actions involve understanding and successfully negotiating the current system, and fully participating in treatment, prevention and data collection activities. Ongoing communications among health system service providers and consumers will be needed to maintain and build upon progress.

Initially, small numbers of providers and consumers can become involved in the competency-building process. Informal, small-group working sessions should supersede any plans for large-scale formal conferences, task forces or planning committees. This will minimize delays resulting from the logistical difficulties of large gatherings and help to avoid the inertia that can accompany large-group planning.

Members of the statewide Ethnic Health Committee could serve as a valuable resources to these activities, with full Committee involvement reserved for reviewing plans, facilitating community support for competency-building activities, examining evidence of progress, and addressing needed refinements identified through a systematic evaluation process. Small-group implementation will allow for early adjustments and accelerated maturation of competency-building activities. Early participants could then remain involved as leaders to guide wider adoption of competency-building strategies.

"When they put these programs together they need to base those programs on our needs...."

"The community should be involved in the planning process; networking system."

"You need to contact the consumers...and sit and talk with the people."

Suggestion 2: Directly involve diverse members of ethnic populations in planning, implementing, and refining actions to address ethnic health issues.

Ethnic populations have endorsed the key informant and planning-style group processes used during this study, and have suggested that this continue on a quarterly or semi-annual basis. Direct involvement goes beyond the activities of representative advisory groups to meaningful participation in guiding the details of health system activities affecting underserved groups. Ethnic populations have a lot to offer in this regard, and have demonstrated an eager and sincere desire to participate in improving health system services to meet the needs of all Utahns. Installing such a process will enhance the acceptability and success of any actions to address the health needs of ethnic populations, and provide an excellent context in which the health system can maintain momentum and accountability.

It may be useful to adopt a development strategy that begins with small programs of manageable scope which can then serve as models for larger-scale efforts in response to identified ethnic health needs. The details of the group-level syntheses presented in this report will be useful to guide the development of new or refined responses to ethnic health needs and data collection strategies. These results must, however, be supplemented by an ongoing effort to obtain more specific direction from ethnic populations.

To be successful, planning for change also needs to involve those who will be asked to make changes. [Investigator comment on best practices]

Suggestion 3: Directly involve diverse members of the health system in planning, implementing, and evaluating next steps.

Involve administrators, educators, direct-service providers, support staff and local professional health organizations in identifying, discussing and responding to self-identified health system issues, and the findings of the qualitative ethnic health study. This will enable health system representatives to make timely adjustments to current practices, and will prepare them to work with ethnic populations in planning, implementing and evaluating actions that respond to the needs of both the health system and ethnic populations.

To ensure progress and accountability, ongoing program evaluation and refinement strategies are needed. [Investigator comment on best practices]

Suggestion 4: Develop and implement plans for assessing health system and consumer progress in addressing ethnic health issues.

A plan incorporating formative, process, and impact evaluation strategies can serve as the basis for organizing all health system ethnic health planning, implementation, and refinement. The primary purpose of evaluation activities would be to inform timely refinements to program activities that will accelerate

system maturation in responding to the health needs of ethnic populations. Evaluation of intermediate impacts such as provider and consumer participation and satisfaction should, in the beginning, take precedence over measuring distant outcomes such as anticipated changes in consumer health status.

“The approach used to conduct [this] survey is a good approach. You talk to people one-on-one.”

“You have to develop trust.” “It’s going to be costly to be well done.”

Suggestion 5: Adopt a blend of quantitative and qualitative strategies when collecting ethnic health information.

Utah’s ethnic populations provided many right-on-target insights and suggestions for collecting information within ethnic communities. These suggestions reflected many of the “best practices” we have incorporated into our work through experience, and those we have identified in the literature. In this report, we have allowed participants’ statements and stories to stand alone as an initial guide to refining data collection strategies in Utah’s ethnic communities. In a separate report we incorporate these comments and the findings from the professional literature into a set of suggestions for planning and conducting the larger quantitative ethnic health survey in 1998.

We are encouraged by the Utah Department of Health’s commitment to Utah’s ethnic populations. We are very impressed by the willing and enthusiastic participation of ethnic population members throughout the state. This for us has been a very stimulating and pleasurable experience. Hopefully, the findings and suggestions of this study will be useful to all in choosing actions that are successful in meeting the health needs of all Utahns.